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ABSTRACT

One of a series of booklets on disability research, this paper explores two major developments in the application of information technology: health care informatics and knowledge management. Both of these concepts focus on maximizing the value of, and access to, information resources. Both use technology to create interactive systems through which a range of individuals and groups can potentially find, exchange, augment, and use information. Informatics, however, primarily looks outward, at consumers, clients, and patients, seeking ways to provide information, products, and services that can make health care more effective and efficient. In contrast, knowledge management looks inward, seeking ways to improve the scope, utility, and efficiency of knowledge within the organization. The first section of the paper discusses health care informatics and functional applications of informatics systems such as online databases, electronic journals, online support groups, computer-based patient record systems, disease management systems, and customer relationship management systems. Individuals who use these systems, and the benefits and advantages to health care informatics are reviewed, along with issues regarding access and information quality and reliability. The second part of the booklet explores knowledge management, how it works, and the importance of knowledge management within a disability research organization. (Contains 30 references.) (CR)

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Shaping Excellence Through Research

General Orientation to New Knowledge Utilization Fields of Informatics, Knowledge Management, and Information Technology

New Knowledge Utilization Fields

SOUTHWEST EDUCATIONAL DEVELOPMENT LABORATORY
SEDL
Building Knowledge to Support Learning

A project funded by the
NIDRR
National Institute on Disability and Rehabilitation Research

U.S. DEPARTMENT OF EDUCATION
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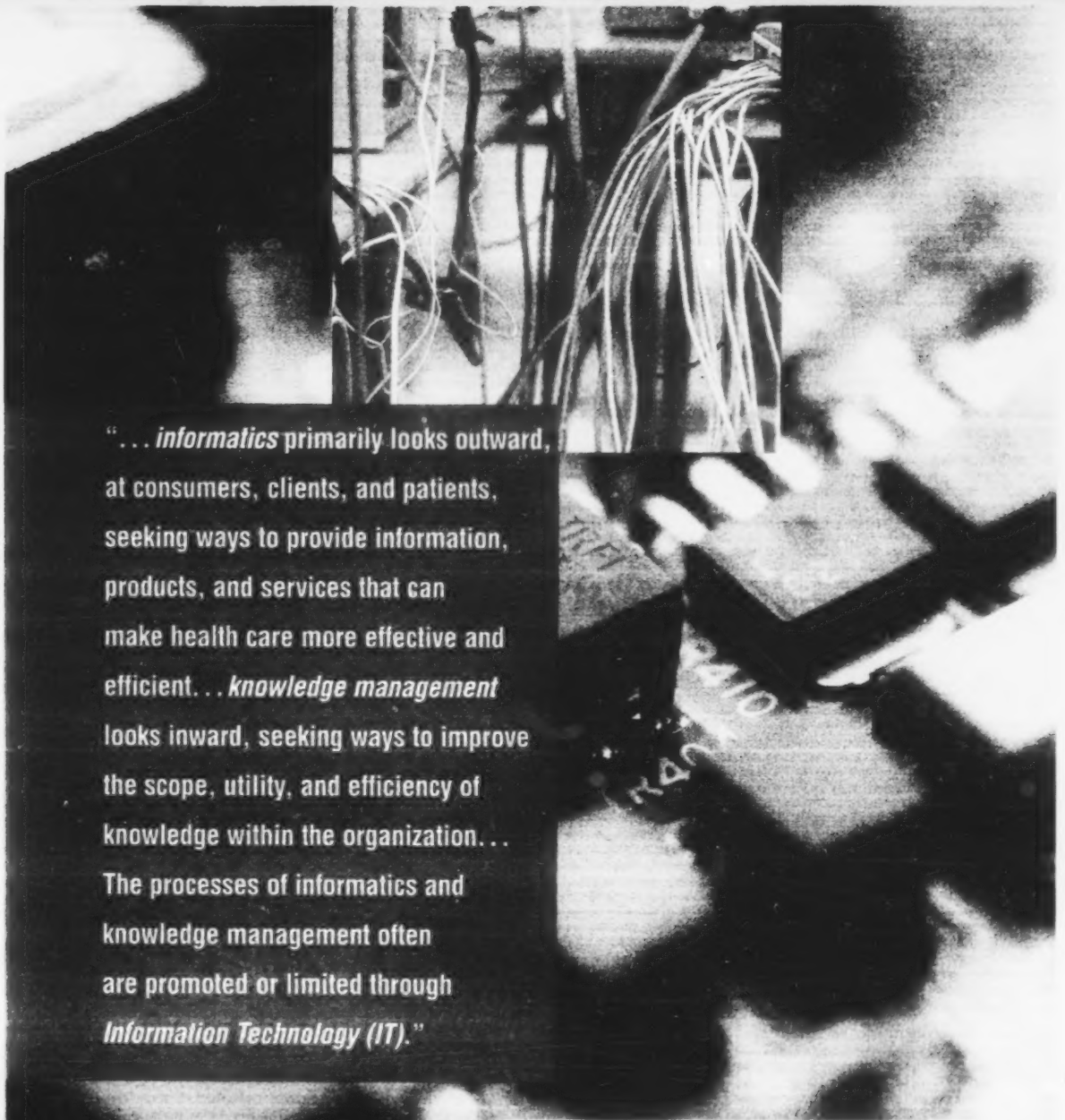

"... *informatics* primarily looks outward, at consumers, clients, and patients, seeking ways to provide information, products, and services that can make health care more effective and efficient... *knowledge management* looks inward, seeking ways to improve the scope, utility, and efficiency of knowledge within the organization... The processes of informatics and knowledge management often are promoted or limited through *Information Technology (IT)*."

Table of Contents

Introduction 1
Health Care Informatics 5
Knowledge Management . . .25
Conclusion 32
References 33
How to Contact the NCDDR . .37

General Orientation to New Knowledge Utilization Fields of Informatics, Knowledge Management, and Information Technology

Information Technology

Introduction

It's impossible, these days, to consider dissemination and utilization strategies without focusing on information technology. If you are a disability researcher, or a service provider whose work includes linking consumers with information resources, you're no doubt well acquainted with tools like online databases, bulletin boards, and CD-ROMs. However, you may be less aware that the power of information technology — especially the twin capacity of *broad access* and *interactivity* — is spawning new conceptions about knowledge utilization, even new disciplines and fields of study. More significantly, information technology is changing our systems of health care, health research, and the provision of health-related information:

> A growing number of policymakers, health care providers, and consumers believes information resources hold the key to improving the health care system. These advocates say that judiciously collected and effectively communicated information can help professionals provide better care, turn patients into enlightened consumers of health services, and ultimately

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> enable individuals and communities to address some of the root causes of illness before professional intervention is required. (Conte, 1999, p. iv)

Technology-based approaches offer significant potential improvements for consumers, caregivers, health-related practitioners, and researchers. However, they are also creating new organizational demands. As one recent report concludes:

> E-health opens up entirely new paths of communication and transactions in healthcare and fosters radically new business patterns and organizational configurations. It also requires new procedures, performance monitoring, change control, approvals and content management capabilities. . . It is fundamentally an initiative of the whole organization. (Lohman, 1999, p. 1)

This paper explores two major developments in the application of information technology: *health care informatics*, and *knowledge management*. Both of these concepts focus on maximizing the value of, and access to, information resources. Both use technology to create interactive systems through which a range of individuals and groups can potentially find, exchange, augment, and use information. Both have developed in large part via the private sector: enterprises seeking to establish new markets and maximize profits as well as to strengthen products and services. And both have generated new organizational structures [for example, IBM's Global Services for Knowledge and Content Management (see: **http://www-4.ibm.com/software/data/knowledge/**), Duke University Medical Center's Division of Clinical Informatics (see: http://dmi-www.mc.duke.edu/)], [job titles (e.g., Chief Knowledge Officer, Director of Knowledge Management Initiatives), training programs (Duke offers a "Medical Informatics Training Program"), and publications (such as Health Care Informatics or

Knowledge Management News
(see: **http://www.healthcare-informatics.com/** or **http://www.kmnews.com/**), both — of course — are available online)].

Where these two concepts differ is that *informatics* primarily looks outward, at consumers, clients, and patients, seeking ways to provide information, products, and services that can make health care more effective and efficient (and, in some instances, more profitable). In contrast, *knowledge management* looks inward, seeking ways to improve the scope, utility, and efficiency of knowledge within the organization.

There are instances where these distinctions blur. Discussions of health care informatics, for example, include strategies for managing patient or client data for internal use related to both planning and service provision. And the goals of knowledge management include improving the quality of services and products as well as strengthening an organization's internal functioning. However, given the current state of distinct literatures on these two subjects, this paper will examine each concept separately.

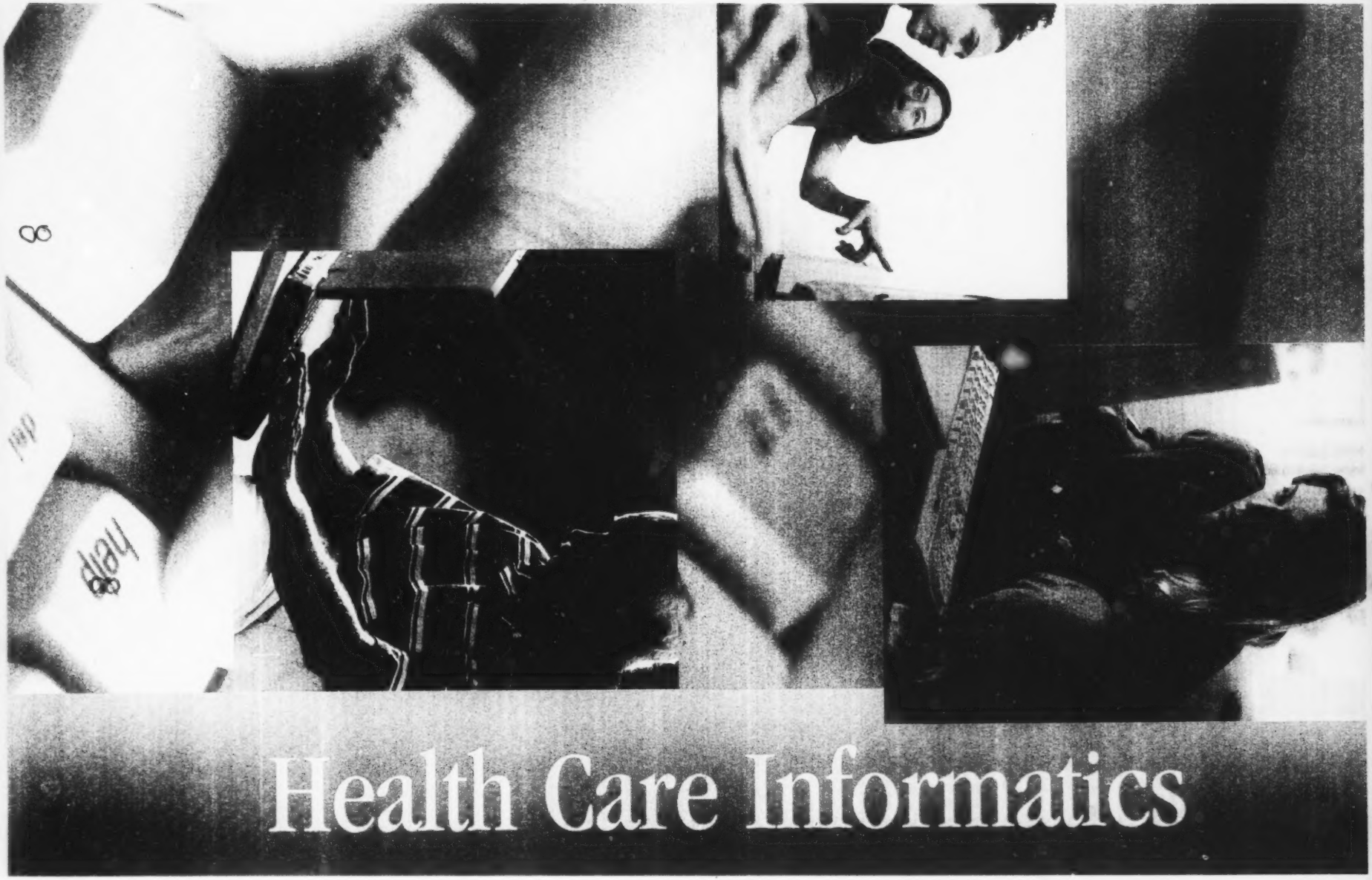
Information Technology

The processes of *informatics* and *knowledge management* often are promoted or limited through Information Technology (IT). The term IT generally refers to computer and related technology applications and mechanisms that promote access and utilization of a variety of digitized text and data resources. IT, then, is a potential vehicle through which information surrounding informatics and knowledge management procedures may be shared.

Since 1980, computers and their use have become increasingly sophisticated. Many features designed to

promote use by the general public have created barriers for people with disabilities. Shortcuts using a computer mouse, for example, to "point and click" create accessibility issues for those that have difficulty seeing the icons or controlling movement of the mouse. IT concepts are now, to an increasing degree, including solutions to reduce barriers for computer users with disabilities. IT practices are being made more accessible through a growing number of federal regulations, such as Section 508 of the Rehabilitation Act of 1973 as amended (Public Law 105-220), and conceptual design procedures such as Universal Design. The increasing accessibility of IT is a fundamental value and requirement for effective and efficient informatics and knowledge management in the 21st Century.

The following pages provide an overview, first, of informatics and, second, of knowledge management, describing basic concepts, applications, issues, and examples. Because of the variety of possible applications, the complexity of issues, and the potential for changing relationships between consumers and providers, informatics is addressed in much greater detail than is knowledge management.



Health Care Informatics

What Is It?

If your health care agency or organization has a Web site, consumer-oriented voice mail system or the like, then you have already entered the field of health care informatics. The U.S. General Accounting Office (1996) describes informatics as "the union of health care content with the speed and ease of technology" (p. 7). More specifically, it defines "consumer health informatics" as "the use of modern computers and telecommunications to support consumers in obtaining information, analyzing their unique health care needs, and helping them make decisions about their own health" (p. 1). Informatics can also extend beyond the provision of information to actual service provision, for example, offering tools for diagnosing problems, monitoring patients' vital signs, or issuing reminders for taking prescription medicines.

Discussions of informatics tend to address "health" issues, with little explicit discussion of "disability," either in terms of consumers with disabilities or of the universe of disability researchers and service providers. Much of the focus within health care informatics, moreover, is on hospitals, health maintenance organizations, and physicians and other medical service providers.

The General Accounting Office report describes three general categories of informatics systems:

1. systems that *provide* health information to the user (one-way communication),
2. systems that *tailor* specific information to the user's unique situation (customized communication), and
3. systems that allow the user to *communicate* and *interact* with health care providers or other users (two-way communication). (p. 7)

At least one more category can be added to this list: systems that provide information to health care providers and researchers, enabling them to improve the effectiveness of services to consumers (Conte, 1999).

The types of information technology used in health care informatics are many and varied. They include computers, Web sites, online bulletin boards, interactive telecommunications systems, hand-held and other wireless devices, CD-ROMs and other software, Local Area Networks, and "convergent technologies," which integrate "data, telephony, email, fax and videoconferencing" (Nine hot trends, 2001, p. 26). Functional applications of these technologies include:

- **online databases** — These include both consumer-oriented and professional-oriented databases. An example is the University of Iowa's "35,000-page Virtual Hospital Web site… For health care professionals, the site provides an array of videoclips, multimedia, textbooks, case studies, and technical descriptions of hundreds of medical afflictions. For consumers, it offers tips on such topics as when to be immunized or screened for cancer, what to expect before and after surgery, how to conduct a breast self-examination, and what should be included in a proper diet." However, information service providers report that the boundaries between consumer and professional use are growing increasingly blurred; a Virtual Hospital (see: **http://www.vh.org/**) developer notes, "We found that patients would read the patient information, and then they would read the provider information, too" (Conte, 1999, p. 6).

- **electronic journals** — As with online databases, there are online journals oriented toward consumers, such as *Healthworld Online*, (see: **http://www.healthy.net/**) and those oriented toward health professionals. There are journals focused on health care informatics, such as the *Informatics Review* (see: **http://www.informatics-review.com/**)

- **online support groups** — Online support groups, which operate via bulletin boards and chat rooms, are proliferating. According to the Benton Foundation, "Electronic chat groups, bulletin board systems, and online forums are easier to attend than face-to-face meetings, so people can participate even if they lack transportation, have scheduling problems, are disabled,

or have 24-hour-a-day caregiver responsibilities. Some online groups also offer participants the option of remaining anonymous even while sharing sensitive information. And electronic meeting places may represent the only opportunity for people with rare disorders to surmount their isolation in their own communities and find similarly situated peers" (Conte, 1999, p. 7).

- **computer-based patient record (CPR) systems** — Many hospitals and health maintenance organizations (HMOs) are planning or implementing comprehensive computer-based patient record systems (Metzger, Amatayakul, & Simpson, n.d.). Often these systems are combined with or linked to other technology applications intended to help health care providers be more timely and responsive to patients. For example, Kaiser Permanente, the largest HMO in the United States, is developing "a computer network electronically linking its 10,000 doctors and nurses to each other and to the Internet. Besides creating standardized medical records for its nine million members, the system will enable doctors to conduct Medline searches and review the contents of medical textbooks, order tests and prescribe drugs, and provide patients with printouts detailing their treatment plans" (Conte, 1999, p. 18). Such systems may also offer new opportunities as data archives for those conducting disability-related research activities.

- **disease management systems** — Disease management systems focus on "motivating and helping chronically ill patients avoid dangerous medical crises... Disease management differs from what's usually called case management in its emphasis on prevention of crisis events. It differs from generalized wellness programs in its tight focus on high-risk, high-cost patients" (Nine hot trends, 2001, p. 14). Disease management applications are gaining in popularity; one expert interviewed by the *Informatics Review* predicts growth by 30 percent each year over the next several years. Another says "that the disease management market should get a major boost soon from two factors: the rapid proliferation of wireless technology and vendors' increased ability to use artificial

intelligence techniques to personalize responses on Web-based platforms. Wireless technology makes communication easier; personalization makes it more effective" (p. 14). One example of a disease management system is CareSteps.com, developed by Texas-based CareSteps, Inc. For HMOs using the system, "Any benefit plan member may receive highly personalized health maintenance guidance, based on responses to a Web-based questionnaire. The program, which is available for about 30 chronic diseases, makes inquiries to find out whether respondents are following the best medical practices. Payors can use the information gathered to stratify the population and identify high-risk cases" (Nine hot trends, 2001, p. 15).

- **customer relationship management (CRM) systems** — Similar to but much larger in scope than disease management systems, "a CRM system isn't a single, self-contained application, like a spreadsheet or a word processor. It's an umbrella term that embraces sales, marketing and customer-service programs... At CRM's core is the simple but radical reorganization of a business around customers — whether they're patients in a hospital or doctors within an [integrated delivery network]" (Nine hot trends, 2001, p. 21). For example, a CRM system may collect information on patients during hospital visits or via personal medical histories. Once such information is collected, "a well-run CRM system can deliver a complete profile... to anyone in an organization who needs it, whether it's a nurse checking medical records or a webmaster gathering statistics." (p. 21) CRMs also use patient profiles to feed information back to consumers, such as strategies for staying healthy, appointment reminders, recommended diets, and the like. Currently, however, CRMs are not widely used; they are extremely costly to implement, and a number of systems have failed because health providers have been slow to use them once development and training supports were removed.

- online health commerce — In a forecasting report on online health consumers prepared for the California HealthCare Foundation, the Institute for the

> Future concluded that "perhaps the most significant opportunities in the next five years will be in the area of online health commerce... Among the most promising are electronic pharmacies, online prescriptions, online pharmacy benefits management, and online health insurance and financing" (Cain, Sarasohn-Kahn, & Wayne, 2000, p. 3).

Demand for health-related IT has led to the proliferation of businesses that provide hardware, software, technical support, and sometimes entire information systems to the health care industry. A recent report on CPR systems notes, for example, that "full-function vendor products that include decision support capability are increasing" (Metzger, et al., n.d., p. 9). Another report discusses the increase in application service providers (ASPs), which "offer attractive options for healthcare enterprises" (Nine hot trends, 2001, p. 8). The report defines an ASP as "an entity that allows clients to tap into and use applications held on an off-site third-party server, usually on a subscription or per-member, per-month basis" (Nine hot trends, 2001, p. 10). Some agencies, however, create their own IT systems, either from the ground up or by a combination of in-house development and outsourcing.

Who Uses It?

Consumers. More and more, in-home users are interested in technology as a way to educate themselves and to access needed health-related information. A recent national survey indicates that "what the American public most desires from the new communications technologies are educational and informational services" (Lake, n.d., p. 1). The increasing demand for health-related information is an important part of this trend. Consider these statistics:

- Telephone inquiries to [the] Public Health Service's information clearinghouses more than doubled in the early 1990s, while mail inquiries grew by 43 percent (GAO, 1996, p. 5).

- A Harris Interactive study in September 1999 found that 70 million of the 97 million American adults who were online had searched for health information in the past year, an increase of 10 million people in just six months (Cain, et al., 2000, p. 1).
- Estimates of the number of health-related Web sites run as high as 10,000 or more... Medline... currently handles an estimated 300,000 searches per day. The Virtual Hospital Web site, an information service for health professionals and patients run by the University of Iowa, gets about four million 'hits' per month (Conte, 1999, p. iv).

The Institute for the Future's forecasting report (Cain, et al., 2000) describes three categories of consumers who are accessing online health information: the well, the newly diagnosed, and the chronically ill and their caregivers. "Well" consumers comprise the majority, or about 60 percent of online health information seekers. For this large group, health information is merely one in an array of categories that interest them: "They search for preventive medicine and wellness information in the same way they look for news, stock quotes, and products" (p. 1). Though "newly diagnosed" consumers make up the smallest group (at about 5 percent of the total), they "search frenetically and cover a lot of ground in the first few weeks following their diagnosis. Many of the newly diagnosed cast a wide net for online information and reach out to enlist the help of a large, diffuse network of family and friends" (p. 1).

The final category, "chronically ill consumers and their caregivers," represents about 35 percent of the total. According to the Institute report, these consumers "have the greatest potential to affect and be affected by Internet health care provision. Many individuals living with a chronic illness actively manage that illness daily and have incorporated that management into their lives," with information-seeking as one ongoing management strategy (Cain, et al., 2000, p. 2).

According the Pew Internet & American Life Project (Pastore, n.d.), "women are much more likely than men to use the Internet to get health and medical information" (p. 2). In general, consumers who use technology to access health-related information are also more affluent and better educated than the U.S. population as a whole (Cain, et al., 2000; Conte, 1999). They also tend to be white and nondisabled (Goslee, 1998; Kaye, 2000). These latter trends are indicators of a Digital Divide that is an increasing concern (see Issues section, below).

Medical service providers. According to at least one source, "the Internet is transforming medical practice for physicians far more rapidly than most industry observers thought possible" (Health Technology Center, n.d.). A Harris survey of physicians' group practices found that "71 percent of physicians in group practices currently use the Internet for medical information and news." More than a third of those polled "consider Internet-enabled core businesses and clinical services to be essential advantages" for future success; such services included "diagnostic reporting, claims processing services, pharmaceutical information, purchase of medical office products, e-mail communication with patients, and electronic medical records" (n.p.).

The adoption by hospitals and HMOs of computerized patient records and disease management systems is also helping to drive changes in use among medical practitioners. For example, Massachusetts General Hospital "has given its neurology residents 'Palm Pilots' to carry on their rounds. Doctors use the portable computers to carry patient data, drug references, lab numbers, and other information" (Conte, 1999, p. 18). However, a study by the Benton Foundation (Conte, 1999) notes "professional resistance" among doctors and other medical service providers as a significant barrier (see Issues section, below).

Researchers. To date, the literature on health care informatics focuses on consumers and service providers, rather than on medical researchers. However, discussions about the advantages of computerized patient record

systems often mention the possibilities for research. If patient information can be standardized, for example within a large HMO or across a number of medical service providers, researchers can access much larger pools of data for clinical trials and comparative studies (Conte, 1999). In addition, the Institute for the Future's report (Cain, et al., 2000) describes the Internet as a useful tool for both promoting and administering clinical trials: "Currently, only 3% of patients eligible for clinical trials are participating in them... The Internet provides a cost-efficient medium for educating patients about what trials are and the value of participating in them as well as a medium for administration of the trials" (p. 57). To address this specific purpose, the National Institute of Health's CenterWatch.com lists more than 40,000 government- and industry-sponsored clinical trials.

What Does It Offer?

The literature describes a number of benefits and advantages to health care informatics, from improving the quality of medical care to making it more convenient for consumers and health professionals to access information. Some of these benefits remain more theory than reality, for example the idea that consumers can compare health plans online, thereby promoting market-driven health care (Conte, 1999). Additionally, some claims are supported — so far — by pockets of data rather than comprehensive studies. Overall, however, the benefits of health care informatics appear to be both tangible and significant.

Four indications of improved **quality of care** include the following:

1 Databases accessible via the Internet are helping to overcome the old truism that "in health care, geography is destiny," i.e., the great regional variations in preferred treatments that have been observed to exist but that "appear to be unrelated to the actual needs of patients" (Conte, 1999, p. 4). According to one federal report, "the average number of Medline citations on randomized

controlled trials increased from 509 annually between 1975 and 1980 to 8,636 a year from 1993 through 1997. These studies, in turn, have led to a dramatic proliferation of practice guidelines spelling out the most appropriate treatment for various medical conditions" (cited in Conte, p. 4).

2 A report from the Pew Internet & American Life Project (summarized by Pastore, n.d.) indicates that "half the people who have used the Internet to get health and medical information say the information has improved the way they take care of themselves... 47 percent of the people who were seeking health information for themselves say the online material influenced their decisions about treatment and care and 36 percent of those seeking information on behalf of others say it influenced their decisions" (p. 1).

3 Awardees participating in a national program that recognizes outstanding quality in the use of computerized patient record (CPR) systems have reported a number of improvements after implementing the CPR system. These include "avoided adverse events (medication-related events in particular), increased appropriateness of care interventions (including medications, blood products, and diagnostic interventions), improved compliance with preventive and disease management protocols, and quicker response to information on changing patient status (e.g., alerts relating to life-threatening situations). Other quality impacts include improved continuity of care... [and] improvements in information timeliness and availability' (Metzger, et al., n.d., p. 8).

4 Although consumers also have substantial privacy-related concerns (see Issues section, below), the use of electronic formats to collect patient data sometimes gives patients a greater sense of freedom in revealing sensitive information. This information, in turn, helps medical providers to offer better care. For example, "an informatics system helped doctors detect signs of alcoholism more quickly when patients completed a computerized interview before an office visit" (GAO,

1996, p. 2). In another study, "a computer questionnaire identified more potential blood donors who had HIV-related factors in their health histories than did personal interviews by health care providers" (p. 13).

Reports on **reductions in health care costs** generally link improved care and reduced costs. These include the following:

- Awardees in the Davies recognition program for outstanding CPR systems report that, along with quality of care, "cost of care is another category of impact. In hospital care in particular, some of the care management improvements [also] avoid costly treatment and longer stays due to adverse events. Improved information access has also reduced utilization of unnecessary repeat diagnostic procedures" (Metzger, et al., n.d., p. 8).
- Providing information to professionals at the point where they make important treatment decisions can improve the quality of care delivered. In a 1994 study, medical libraries performed literature searches and forwarded relevant citations to doctors at the time their patients were admitted to three Detroit hospitals. The patients on average had 65 percent shorter hospital stays — and comparably lower hospital bills — than patients in a test group (Conte, 1999, p. 18).

There are also strong indications that health-related information technologies are helping to develop **more self-reliant consumers**:

- The boundaries between experts and lay people are starting to blur. Today's Internet-savvy patients are coming to their doctors' offices armed with more information and better questions than the passive patients of the past. Occasionally, patients even tell their doctors about new research findings and experimental treatments, rather than the other way around (Conte, 1999, p. 6).

- According to the Pew report (Pastore, n.d.), consumers note that "information from the Web helped them decide how to treat an illness, prepared them to ask more questions of their doctors or seek second opinions, and helped them decide whether to go to the doctor or not" (p. 1).

In its report on consumer health care informatics, the U.S. General Accounting Office (1996) also listed several **other advantages** of health care informatics systems. These include:

- *anonymity* — increased ability to remain unknown while accessing personal or sensitive information, allowing a more accurate representation of health data;
- *outreach* — improved access by individuals in rural and underserved areas;
- *convenience* — the ability to use the system any time, day or night;
- *scope* — increased ability to reach large numbers of people; and
- *support* — ease of establishing on-line relationships with others. (p. 13)

Health care informatics is not a thing of the future. With online queries in the millions, and with service providers on the scale of Kaiser Permanente implementing informatics systems, not only is informatics here, it is rapidly entering the mainstream. Nevertheless, a number of significant issues and barriers remain. These include:

- unequal consumer access to technology-based information and services;
- variations in the quality and reliability of information available to both consumers and professionals;
- inaccessible hardware and software design;
- issues regarding reliability and availability of technology systems themselves;

- concerns about protecting consumers' privacy while making essential information available to health providers;
- health providers' resistance to relying on technology, and to the changing relationships with consumer that accompany broad information access;
- problems with compatibility and a lack of standardization among hardware, software, and health-care data; and
- costs for developing, implementing, and maintaining technology systems.

Issues

Consumer access. The issue of access has two dimensions. The first, and most basic, is physical access to computers, to telephones, and to health service providers that are adopting informatics systems to improve patient care and to lower costs. Surveys show that people with low incomes, ethnic/racial minorities — particularly African Americans and Hispanics —, and people with disabilities may be less likely than the population as a whole to have access to computers and the Internet:

- Americans with disabilities are less than half as likely as their non-disabled counterparts to own a computer, and they are about one-quarter as likely to use the Internet. (Kaye, 2000, p. 1). Only 23.9 percent of people with disabilities have a computer in the household, compared to 51.7 percent of nondisabled Americans. About 9.9 percent of Americans with disabilities connect to the Internet, compared to 38.1 percent of the nondisabled population.
- A 1998 consumer technology survey found that 80 percent of families with incomes over $100,000 have computers, while only 25 percent of families with incomes under $30,000 have computers (reported in Goslee, 1998).

- Another 1998 study found that 53 percent of people with an undergraduate degree or more use the World Wide Web, as opposed to only 19 percent of those with a high school education or less (reported in Goslee, 1998).
- There is some evidence that race and income may interact in troubling ways. A 1998 Vanderbilt University study... indicates that racial inequities in computer ownership and Internet access jump significantly when household incomes drop below $40,000 (Goslee, 1998, p. 3).
- Though computer and Internet use varies according to income, education, and race, within each of these categories, people with disabilities are less likely than others in the category to own computers or use the Internet (Kaye, 2000).

The National Center for the Dissemination of Disability Research has reported trends regarding computer use from its annual survey of people with disabilities (NCDDR, 2001a, 2001b). Major findings of the survey include:

- Internet access at home was reported by 48 percent of the consumer group sampled;
- Nearly one-third of the consumer group reported using the Internet at a community-based Independent Living Center;
- 35 percent of the consumer group reported using the Internet on a daily basis;
- When searching for disability-related research information, 56 percent of the consumer group indicated they use the computer; and
- Of the consumers with a computer at home, 81 percent indicated they preferred receiving disability-related research information via the computer.

There are also gaps in access at the community level; many rural and inner city areas lack the infrastructure necessary for reliable, high-speed Internet access and other

technology-based resources (Goslee, 1998; GAO, 1996). A report on the Digital Divide by the Benton Foundation (Goslee, 1998) points out that:

> While public attention is often focused on whether individuals can get a service, the equally important problem is that lack of adequate telecommunications facilities makes an area less attractive for businesses. This can feed a spiral where the lack of investment at the community level leads to fewer economic opportunities for people who live there... The same neighborhoods that lack infrastructure are comprised of households that are far less likely to have the tools of the Information Age. (p. 2)

Although home is not the only available point of access to technology resources, public institutions such as schools and libraries do not offer a comprehensive solution for those who cannot afford to have technology at home. As the Benton Foundation report notes, "many of these institutions mirror the technology gap rather than mitigate it" (Goslee, 1998, p. 7). Internet access and other technology resources are spread unequally among schools and libraries; this is especially true for libraries, since "ninety percent of library funding is local" (p. 8).

A major second dimension to this issue is access to the technology skills, analytical skills, and contextual understandings that are essential to consumers' ability to find and evaluate information and then use it effectively to influence health-related decisions and behaviors. As one report concludes, "Addressing the access problem will require more than installing hardware. Even many people with access to online resources lack the skills to use health information proactively" (Conte, 1999, p. 10). This conclusion is reinforced by the Pew Internet & American Life Project report (Pastore, n.d.), which states:

> The research also found that the search strategies of online health seekers are scattershot. Most report that the last time they went online looking for health information they found what they needed. But they also relied on Internet searches without the benefit of professional advice, and often got information from Web sites they had never heard of before they began the search. (p. 1)

Information quality and reliability. Assuring the quality and reliability of information content is a major issue for health care informatics. Experts surveyed by the U.S. General Accounting Office (1996) ranked it among their top three concerns, and a national Committee on Enhancing the Internet for Health Applications (n.d.) concludes:

> The paramountcy of safety — individuals' health and lives are at stake, after all — requires that information not be corrupted before, during, or after transmission across the network from one party to another. Although security is also important in many other Internet applications..., health applications pose special challenges. (pp. 5-6)

There are concerns about the quality and reliability of information that can be accessed by consumers via online databases, electronic journals, and the like. Experts queried by the U.S. General Accounting Office (1996) noted "the potential for information to be incomplete, inaccurate, or outdated" (p. 16). Moreover, as Conte (1999) reports:

> On the World Wide Web, information presented by prestigious research institutions exists side by side with self-serving commercial sites and outright scams... Last year, in the first "International Health Claim Surf Day," 80 agencies and organizations explored the Internet and found 1,200 sites proclaiming mechanical devices that miraculously treat the pain of arthritis, herbal remedies that

> ward off AIDS, mysterious elixirs that cure cancer, and other potentially false or deceptive advertising health claims. (p. 11)

Fortunately, at least some studies show that many consumers have a healthy skepticism of online information (Conte, 1999). Concerns about information quality and reliability can escalate to the level of life and death, however, when the information consists of (1) material used by physicians and other health providers in diagnosing or treating illnesses, or (2) patient records. A report on the Davies program awardees for high-quality computerized patient record systems notes that "data integrity is viewed by the awardees as one of the biggest problems with which developers struggle, and each awardee has invested in multiple approaches to increase data integrity" (Metzger, et al, n.d., p. 6).

There are multiple ways for data to be corrupted: through incorrect initial entry, problems with hardware and software, and malicious tampering. One particular disturbing fact is pointed out in the online magazine, *Healthcare Informatics*, which states that "healthcare already has quite a reputation among hackers" (Nine hot trends, 2001, p. 3). In many instances, hackers are not interested in the healthcare facility's own data or network; rather, according to one expert, "Their networks are so easy to break into that they're easy targets. But people aren't necessarily looking for information on that network; they're looking for a launching point for an attack against another network" (p. 3).

The proliferation of wireless and handheld technology has led to additional security issues. With "mobile use of health information — personal digital assistants, wireless and laptop computers — and what's stored on the device as it's carried around," there are increased opportunities for data, and the devices themselves, to be lost or stolen (Nine hot trends, 2001, p. 3).

Reliability and availability of technology systems. Particularly when information is used to help with the diagnosis, treatment, or monitoring of patients, issues of reliability and availability encompass not only information content but the technology used to deliver that content. The Committee on Enhancing the Internet for Health Applications (n.d.) concludes:

> High levels of availability are needed in mission-critical applications in many industries... But the health sector's need for high levels of network availability to and from a large number of possible locations can also be greater than in other sectors, because health, well-being, and even life may be at stake. If care providers are to use the Internet to access electronic patient records when treating patients in the emergency room, they must know that the network and the applications are operational 24 hours a day, 7 days a week. (p. 6)

Privacy. Also related to information security is the concern for patient and consumer privacy. Several sources (e.g., Conte, 1999; GAO, 1996) note that privacy is a major concern for consumers. Information from the Pew report (Pastore, n.d.) is characteristic:

> Most Internet users are worried about their online privacy, especially when it comes to their medical information. Nearly 90 percent (89 percent) of health seekers say they are worried that Internet companies will collect and share data about the Web sites they visited; 85 percent say they fear that insurance companies might change their coverage after finding out what online information they accessed; and 52 percent fret that their employers might learn what kind of medical material they accessed... 63 percent of health seekers oppose the idea of keeping medical records online, even at a secure, password-protected site, because they fear other people will see those records. (pp. 1-2).

Professional resistance. At least one major study identifies "professional resistance" among medical service providers as a barrier to the widespread use of informatics in the actual provision of health care services. The Benton Foundation report (Conte, 1999) notes that, "lacking training and basic familiarity with information tools, many physicians have a common reaction to the so-called 'information revolution.' They are overwhelmed" (p. 12). The report also notes another dimension to doctors' resistance:

> The increased public availability of unfiltered information also can complicate doctors' relationships with patients. Some physicians complain, for instance, about patients coming into their offices armed with misinformation and cockeyed ideas they picked up in chat rooms and obscure Web sites. (p. 13)

Compatibility/standardization. Also of significant concern are issues related to compatibility among both hardware and software, and to the need for common standards for health-care data (Conte, 1999; GAO, 1996). As the report by the Committee on Enhancing the Internet for Health Applications (n.d.) observes:

> Despite some consolidation over the past decade, the [health care] sector is very diverse and decentralized and marked by local solutions to problems — it has been characterized as a "trillion-dollar cottage industry." As a result, effecting wide-scale change can be difficult, as is achieving a unified voice on issues of technology and its application. (pp. 7-8)

As one example of compatibility issues, a *Healthcare Informatics* article describes one medical center employee who "is using hand-helds on prescription order entry, wireless dictation and rounds reports." The employee reported that "all three applications require a different device... I can't even do two applications on the same device because one of them [runs on] Windows CE, one

of them is a full-blown client and the other is a Palm Pilot application" (Nine hot trends, 2001, p. 6).

Other issues. The U.S. Government Accounting Office (1996) report on consumer informatics also identifies several issues related to the proliferation of technology-based information targeted to consumers. One is cost, a factor that, though not singled out in other reports, is discussed in relation to many specific concerns and their potential solutions. Another issue mentioned by the GAO is copyright, with concerns related both to the need to protect the developers of software and information content, and to the need for broad access and portability. Finally, the GAO report noted that, in reviewing a draft of the report, officials from the U.S. Department of Health and Human Services noted that "a counterbalancing issue to informatics quality is the potential for 'censorship' " (p. 26).

Knowledge Management

What Is It?

The field of knowledge management has developed from the principle that the knowledge held within an organization — including staff expertise and experience, data files, development processes, and the like — are important resources that can improve the organization's productivity, creativity, and/or profits. Bukowitz and Williams (1999) define knowledge management as "the process by which the organization generates wealth from its intellectual or knowledge-based assets" (p. 2). The functions of knowledge management, these authors say, are to:

- create more efficient and effective processes,
- create customer value, and
- boost innovation and promote the development of unique market offerings. (p. 2)

Another guidebook (Koulopoulos & Frappaolo, 1999) notes that "knowledge management emphasizes the re-use of previous experiences and practices, but its focus is on mapping these to the changing landscape of the market" (p. 16).

As the language used in these descriptions suggests, the literature on knowledge management generally focuses on corporate environments, with an experience base drawn primarily from private enterprise. In most instances, then, the ultimate purpose of knowledge management is to boost profitability. And unlike informatics, which is a technology-related set of approaches emerging specifically from the health-care industry, knowledge management is an approach that has been used in a great range of enterprises, from jeans manufacturers to dot.com companies.

Although knowledge management approaches (often abbreviated in the literature as KM) are usually technology based, experts stress that "KM is not embodied by a software application as much as it is a business discipline" (Grammer, 2000, n.p.). Thomas Davenport, a professor of information management, coined the alternative term "information ecology," because he sought to emphasize "an organization's entire information environment," including:

- all of a firm's values and beliefs about information (culture);
- how people actually use information and what they do with it (behavior and work processes);
- the pitfalls that can interfere with information sharing (politics); and
- what information systems are already in place (yes, finally, technology). (Davenport, 1997, p. 4)

Other experts talk about "knowledge-creating" companies (Nonaka, 1998), or "learning organizations" (Garvin, 1998). Whatever the labels, however, the focus is on developing "an organization skilled at creating, acquiring, and transferring knowledge, and at modifying its behavior to reflect new knowledge and insights" (Garvin, 1998, p. 5).

What Does It Address?

Knowledge management systems attempt to reap benefits from two broad types of knowledge residing within an organization: *explicit* knowledge and tacit knowledge (Nonaka, 1991, cited in Bukowitz & Williams, 1999). Bukowitz & Williams, in explaining the distinction between the two, describe explicit knowledge as "knowledge that the individual *knows* she knows," while tacit knowledge is "knowledge that the individual *does not know* she knows because it has become embedded in the way she works" (p. 4).

With both types, the basic challenge is to find ways of capturing and sharing knowledge with others who need it. With tacit knowledge, however, there is the additional task of bringing the information "to a more conscious level," (Bukowitz & Williams, 1999, p. 4), a task that can require "skilled observation, facilitation, and interviewing techniques" (p. 5). Some new technologies, such as video-conferencing, can help to facilitate the sharing of tacit knowledge, through online discussions and debriefings.

Though tacit knowledge can be much more difficult to access and share, experts note that "an organization's most valuable knowledge is often tacit... There is no doubt that tacit knowledge plays a more important role in distinguishing companies in times of success" (Koulopoulos & Frappaolo, 1999, p. 46).

The literature on knowledge management focuses principally on process rather than on content, leaving the content focus of KM initiatives to the judgment and needs of each organization. Knowledge content categories that do receive specific mention include customers, product innovation, and costs (Manasco, n.d.a). Of these, customer knowledge appears to receive the greatest attention. Knowledge management consultant Britton Manasco (n.d.a) identifies three components of "customer knowledge":

- knowledge *of* customers (who they are and what they want);
- knowledge *about* customers (key attributes, problems and issues, transaction history, likelihood of purchasing again); and
- knowledge of the customer's *environment* (business and personal situations, *their* customers' problems and issues, affinity groups). (p. 2)

How Does It Work?

Knowledge management systems can be extremely complex. In much of the literature you will find elaborate conceptual models, multi-step procedures, lengthy diagnostic tools, even strategies for grouping knowledge management teams according to personality types as well as by job function. In practice, however, knowledge management approaches are often more basic and straightforward. Davenport (n.d.), for example, worked with two other researchers to interview managers of more than thirty different knowledge management projects. They found that most projects "involved some kind of repository — a 'bucket-o'-knowledge,' one might call it," and that these repositories generally fell along a continuum:

- One set of projects could be characterized as highly structured, consisting most commonly of documents, such as white papers.
- A second set was less structured, "consisting of the insights and observations of employees." According to Davenport, "these repositories might be called 'discussion databases' or 'lessons-learned' systems."
- The third set of projects used a repository that "holds not knowledge itself but pointers to those who have knowledge," such as corporate yellow pages, a popular strategy (p. 1).

Although the use of repositories — databases, online libraries, yellow pages, even employee Web pages that describe staff members' experiences and observations about their work (Collison, 1999) — is characteristic of many knowledge management applications, "knowledge management depends less on the amount of information than on the number of connections that link information and people" (Koulopoulos & Frappaolo, 1999). Experts note that "the dynamic linking aspect of knowledge is a critical distinguishing factor between knowledge management and information management" (p. 20).

In addition to repositories, or "knowledge libraries," Koulopoulos and Frappaolo (1999) identify two other major categories of knowledge management activity. One is "the learning organization," an approach that "is oriented towards cultural reform of organizational attitudes and practices surrounding knowledge." This approach generally incorporates the use of knowledge management teams, or "learning teams" (p. 60). The third category is known as "mission-critical awareness," or "knowledge warehouses":

> The knowledge warehouse contains information about products, distribution channels, customers, competitors, and suppliers... The warehouse integrates the collected information into a logical model of different subject areas and makes this information accessible across the enterprise

> Just-in-Time, when it is required by users to enhance their work. (p. 66)

From their interviews, Davenport (n.d.) and his colleagues identified several critical elements that influenced the effectiveness of knowledge management strategies. These included support from senior management, "clarity of objectives and language" used to describe the KM initiative to employees, and "a strong focus on... motivating workers to share and use knowledge." The researchers found that "technology infrastructure was apparently necessary but not sufficient... Creating an organizational infrastructure — a set of roles and skills for managing knowledge — seemed just as essential" (p. 2).

Issues

Discussions of issues and requirements related to knowledge management also often tend to be complex and linked to specific conceptual models for the KM process. However, one basic criticism filters through the rhetoric: the tendency for organizations and employees to focus on the technological aspects of the knowledge management systems rather than on the importance of knowledge-sharing for strategic purposes (Zack, 1999; Davenport, 1997). As Davenport observes:

> When managers at all levels fail to take a broader approach to information use, there are real consequences: from millions of dollars wasted on unnecessary technology to salespeople who don't understand how to use a customer database more effectively. Ironically, as information becomes ever more important to us, we must learn to think beyond machines. (p. 6)

Knowledge management seems particularly important within a disability research project/organization context. Effective gains through research are accomplished when past efforts are remembered and used to shape the current and future research design. Understanding from a variety of

research contexts enhances and enriches the ability of the researcher to investigate and secure new knowledge from the research effort. Without effective knowledge management within the research organization, each research activity will continue to exist within a narrow and splintered framework rather than an integrated research-based context. Disability research findings only become important when their appropriate and most beneficial application within the real-world context are clearly understood.

Conclusions

In spite of their general orientation to private enterprise, both informatics and knowledge management offer ideas and approaches that can be valuable to disability researchers and service providers. A customer — or consumer — centered orientation, a belief that "health care is an information business" (Metzger, Amatayakul, & Simpson, n.d., p. 1), and a focus on obtaining maximum value from information resources — all these are important concepts with broad applicability.

In terms of D&U, what these two disciplines — and particularly health care informatics — offer is an orientation toward increasing *interactivity* between information and users. The literature on dissemination has long asserted that the task of disseminating information does not end until the intended audiences are actually using the ideas, materials, or products being disseminated. For years this idea remained more a theory than reality. Now, however, technology-based approaches are increasingly blurring the lines between dissemination and utilization. This merger is reflected in a definition of knowledge put forth by knowledge management consultant Britton Manasco (n.d.b):

> Knowledge is information put to work; it requires an application. Knowledge is information that makes a difference. (p. 1)

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